



Statistics

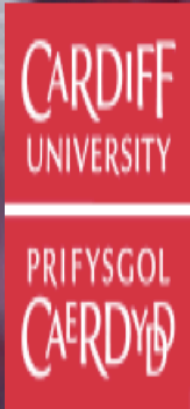
total distance: 3153,82 miles

total activities: 1000

total calories: 1010560

weight: 155,00 lbs

eHealth, ethics and  
privacy



# School of Social Sciences

## ME

Dr. Roser Beneito-Montagut  
Lecturer in Digital Social Sciences  
Cardiff University  
Researcher at CareNet  
Universitat Oberta de Catalunya

Data collection / generation challenge  
Privacy challenge  
Anonymity challenge  
Ethics of care

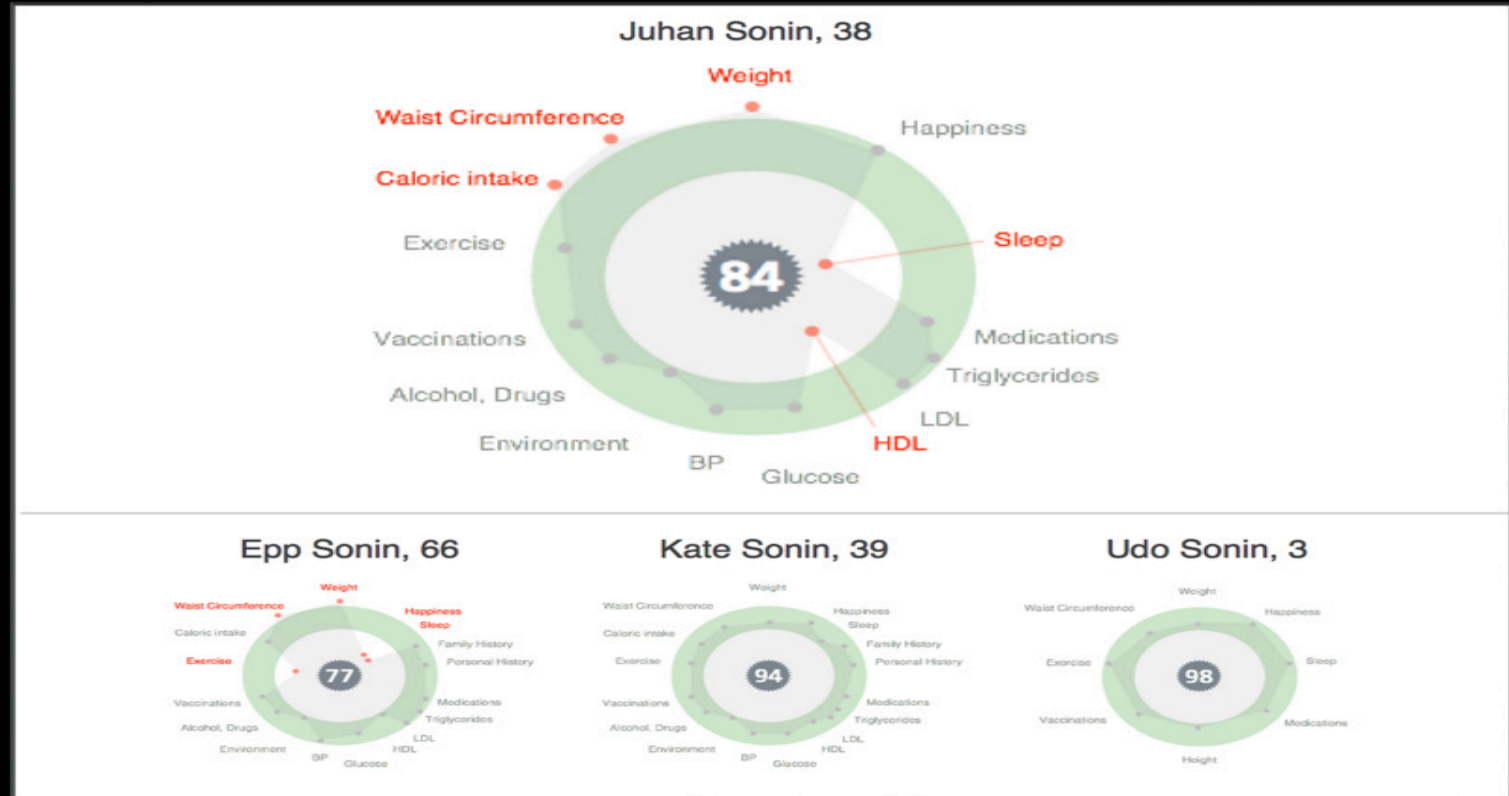




from UHN eHealth Innovation

# communication





hGraph basics + multi screen by Juhan Sonin (CC BY 2.0)

context & settings



Exercise by Eric Veland (CC BY-NC 2.0)

context & settings



# mHealth

A photograph of a smartphone with a blue protective case lying on a light-colored surface. The phone's screen is on, showing a red ECG (heart rate) line. A white charging cable is plugged into the bottom of the phone. In the background, a white laptop keyboard is partially visible and out of focus.

eHealth

Exercise by Andy Miah (CC BY-NC 2.0)

## context & settings

# 6 CHARACTERS REBOOTING MEDICINE AND HEALTH

# 0, 1, A, C, G, T

Brought to you by MI2FIT and  
linkd.in/DigitalHealthGroup  
[www.misfitwearables.com/references](http://www.misfitwearables.com/references)



## Accelerating Digital Technology

## Super-Convergence

## Reboot

64M

16M

4M

1M

250K

2

Number of sequenced Human Genomes

PREVENTION

PREDICTION

MANAGEMENT

DIAGNOSIS

DISEASE

Wireless Sensors  
& Devices

{10110001010101010101010101010101}

Mobile  
Connectivity

{01101010010101010101010101010101}

Social  
Networking

{101101001100010110101010101010101}

Genomics {ACGTACGTAGTACGACGTTAGCCT}

Internet

{10100100101001001101010101010101}

Imaging

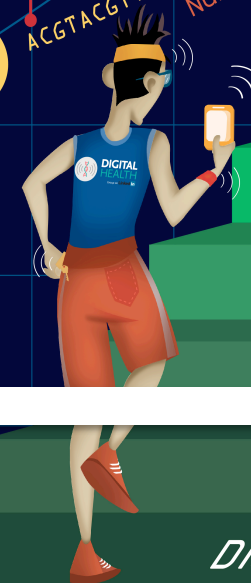
{010100101110100110101010101010101}

Data Universe

{10101010110101010101010101010101}

Health Information

{101010101010101010101010101010101}



Acceleration of Digital Technology

Digital Health Infographic by Paul Sonnier (CC BY 1.0)

1970 1980 1990 2000

Based on the work of Dr. Eric Topol, author of "The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care"

2010

2020





Apps

My apps

Shop

Games

Family

Editors' Choice

Search

Android Apps

All prices

All ratings



## Apps



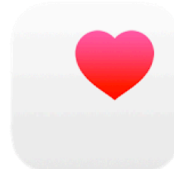
S Health  
Samsung Electronics C

★★★★★



Google Fit - Fitness  
Google Inc.

★★★★★



Health Kit  
Asim Inc

★★★★★



Microsoft Health  
Microsoft Corporation

★★★★★



Health and Nutrition  
naveeninfotech

★★★★★



Health Manager  
EZHIL

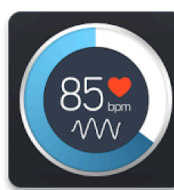
★★★★★



Health Tracker



Pedometer



Instant Heart Rate



Healthy Recipes



10 Daily Exercises



Pedometer & Weight

Pew Research Internet Centre (2015)

Health & Fitness

28,617 / 2,75%

Medical

14,632 / 1,41%

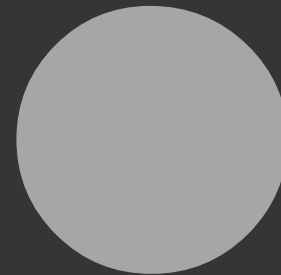
What ethical obligations do researchers have to protect the **PRIVACY** of subjects engaging in activities in Internet spaces?

How is **CONFIDENTIALITY** and **ANONYMITY** assured online?

How is and should **INFORMED CONSENT** be obtained online?



researchers & data







<http://i.huffpost.com/gen/1897543/images/o-PRIVACY-facebook.jpg>

Terms of use, privacy policy &  
permissions

## Permissions

Permissions that access user information

EU – Draft of conduct

### App Permissions Vary a Bit by Category

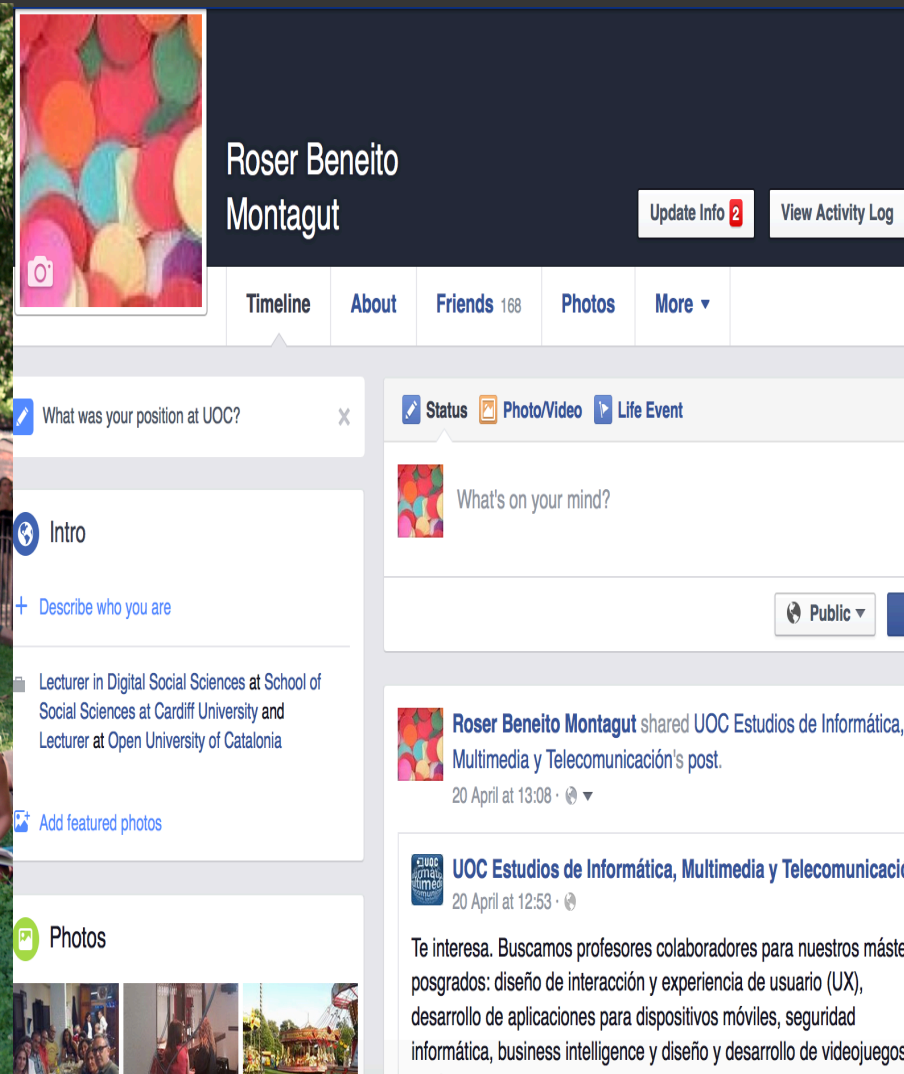
| Category         | Average (mean) # of Permissions | Category          | Average (mean) # of Permissions |
|------------------|---------------------------------|-------------------|---------------------------------|
| Communication    | 9                               | Education         | 5                               |
| Business         | 8                               | Entertainment     | 5                               |
| Casino           | 7                               | Family            | 5                               |
| Lifestyle        | 7                               | Health & Fitness  | 5                               |
| Role Playing     | 7                               | Medical           | 5                               |
| Shopping         | 7                               | Music             | 5                               |
| Social           | 7                               | Productivity      | 5                               |
| Transportation   | 7                               | Racing            | 5                               |
| Travel & Local   | 7                               | Simulation        | 5                               |
| Finance          | 6                               | Tools             | 5                               |
| Media & Video    | 6                               | Trivia            | 5                               |
| Music & Audio    | 6                               | Weather           | 5                               |
| News & Magazines | 6                               | Arcade            | 4                               |
| Photography      | 6                               | Board             | 4                               |
| Sports           | 6                               | Books & Reference | 4                               |
| Strategy         | 6                               | Card              | 4                               |
| Action           | 5                               | Casual            | 4                               |
| Adventure        | 5                               | Comics            | 4                               |

Source: Google Play Store, June 18-Sept 8, 2014.

Note: "Games" was expanded into its subcategories for this list. 8 apps did not have category information.

PEW RESEARCH CENTER





[The central knoll at Tompkins Square Park CC BY-SA 3.0](#) David [Shankbone](#)

Private & public  
 “...privacy is a concept that must include a consideration of expectations and consensus.” (AoIR 2012)  
 Contextual integrity

# Are we studying human subjects?

- A study of email communication
- Interviews in virtual worlds
- Forums, IM
- Web crawlers
- Third-party applications

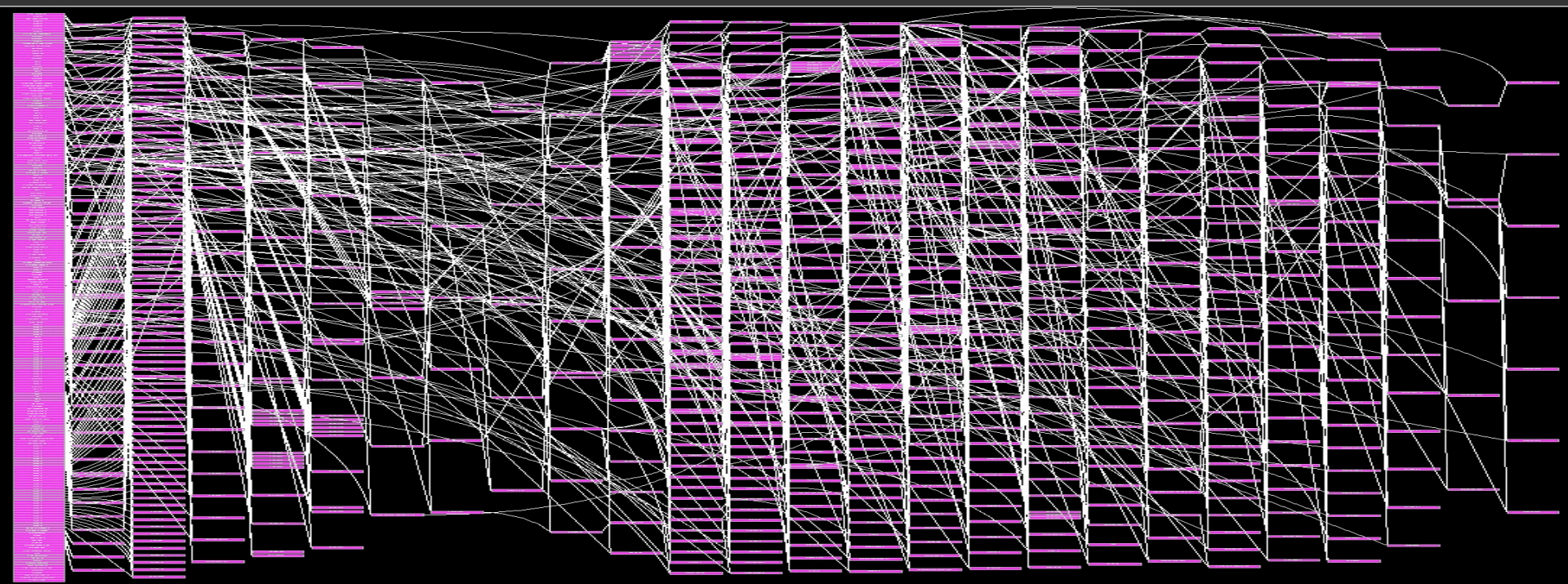
- Large data pools. Eg. #hashtag in Twitter.
- Big social data
- The connection between the person and the object of research is indistinct.

**INFORMED CONSENT**

**ANONIMITY**

Aggregated data  
Confidentiality & Anonymity  
Data / human subjects





Johnclark.pba CC-BY-SA-3.0

# COMPLEX

EU – Draft of conduct

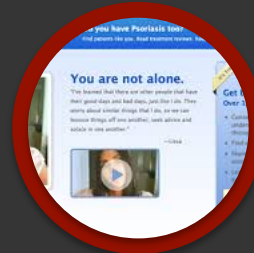
AoIR Research Ethics Guidelines (2012)

Ethics Resource Guide (COSMOS)

Individuals



Socio-technical  
context



Circumstances

ETHICS OF CARE



# Thanks

[Beneito-montagutR@cardiff.ac.uk](mailto:Beneito-montagutR@cardiff.ac.uk)  
@roserrr